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AUTHOR McCorkle, Ruth
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ABSTRACT

A non-experimental, exploratory field study was designed to investigate the impact of a diagnosis of nonresectable lung cancer on eight subjects' relationships with others and plans for the future. Participant observation, systematic verbal and behavioral communications between subjects and investigator were the primary methods of inquiry. Such data as information concerning diagnosis and prognosis transmitted by physician, and subject's behavior in relation to family and significant others were collected. The results of these data suggest that different communication strategies are needed to help the individual and his family cope with the situation. Return visits may be an appropriate time for a systematic approach to problem-solving by a trained health care professional. (KS)

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Communicating with Patients with a Life-Threatening Illness and Their Families

Submitted by:

Ruth McCorkle, R.N., Ph.D.
Assistant Professor
Department of Comparative Nursing Care Systems
School of Nursing
University of Washington
Seattle, Washington 98195
1-206-543-7134

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Communicating with Patients with a Life-Threatening Illness and Their Families

Introduction

There are no clear cut guidelines to describe what to say to patients with a terminal illness, who should say it, and how it should be said, and when. Traditionally, the physician has always been the major determinant of what information is formally given to a patient about his diagnosis.[1] In special cases acknowledged by the physician, the task may be delegated to someone else such as a family member, nurse, or minister. This paper will focus on the extent to which physicians communicate with patients with a terminal illness that their death is or is not imminent after a diagnosis of non-resectable lung cancer is made. This paper is one segment of a comparative study to describe the impact of a life-threatening illness on a person's relationships with others and the person's plans for the future throughout his illness.[2]

There are many events that may be perceived as threatening to a person, his relationships with others and his goals for the future. The individual's perception of the event as threatening requires an interpretation by the person himself about the significance of the stimulus situation. This interpretation process is called appraisal by Lazarus. A stimulus may be perceived threatening to one individual and nonthreatening to another. "The threat is not simply out there as an attribute of the stimulus. Rather it depends for its threat value on this appraisal, which in turn depends upon the person's beliefs about what the stimulus means for the thwarting motives of importance to him."[3]

When an event occurs that is perceived as personally threatening, stress occurs that manifests itself in a period of disequilibrium. A crisis results as a person's homeostatic mechanisms are overpowered by disequilibrium. During this time, the individual finds himself faced with a problem that is of basic importance to him because it is linked with his fundamental instinctual needs and is not quickly solved by his normal problem solving mechanisms.[4] Parad and Caplan recognize that hazardous life events such as pregnancy, birth, important role transitions, and incapacitating illness are capable of inducing crisis reactions which are difficult to solve by familiar methods and are of basic importance to the person's needs.[5]

Hospitalization may be one such event and is recognized by many as a threat to the individual's personal integrity no matter what the nature of the illness. Admission represents a personal crisis in the patient's life and for all concerned it becomes a turning point in the person's efforts to cope with illness.

The Impact of Cancer

An illness associated with a cancer diagnosis may have an additional effect on the individual's perception of what is happening to him. The meaning of that diagnosis is a personal experience for each in whom it occurs, and there is general agreement that many believe that a diagnosis of cancer means they will die.[7] In Feder's interviews with one hundred cancer patients, he identified that the patients did not view death as their greatest threat but rather were fearful of pain, helplessness, rejection and progressive isolation. However, in contrast he cited that the physician's major concern was with the ultimate outcome of the disease.[8]

Certainly cancer and the fear it creates must be respected merely because it is the second leading cause of death among adults in the United States. One out of every four people in America will eventually have cancer. Over one thousand people die a day or about one person every one and one half minutes dies.[9] The fear that people experience has been recognized as the major cause of delay in persons seeking medical advise for their symptoms.[10,11] In spite of that fear, for many, the advances of modern detection techniques and early treatment are resulting in their becoming free of their disease once treated. And yet there are many in whom the disease continues to progress beyond the possibilities of treatment. For those individuals they are suddenly faced with the uncertainties of what to expect and how to manage what is happening to them and their family for their remaining days together.

There are numerous references on whether cancer victims should or should not be told their diagnosis and prognosis. There is general agreement that the argument against telling is associated with the anticipation of profoundly disturbing psychological effects.[12] These disturbing psychological effects have been investigated in some detail.[13] The debate whether to tell or not tell has been studied and presented as if it is a dichotomous issue and as if telling is equated with understanding. The more important issue may not be the verbalization of the word "cancer," but the issue of how that person is helped to manage what time he has left with his family.

Method of Study

A non-experimental, exploratory field study was designed to investigate the impact of a diagnosis of nonresectable lung cancer on an individual's relationships with others and the individual's plans for his future over time. A sample of eight subjects, six males and two females, were followed from the time they were diagnosed until they died. (See Table I) Subjects were interviewed in the hospital setting and their homes throughout a series of contacts as the patient's illness progressed.

The interviews were informal with a minimum of direct questions. They were not scheduled for specific length of time and were generally focused on the subject's thoughts and feelings concerning the contacts or absence of contacts with others. The richness of the data was dependent upon the investigator eliciting and sustaining cooperation with the subjects and the persons identified as important; therefore the first few contacts were used to establish rapport with the subjects.

Data Collection

Participant observation [14] was the primary method used by the investigator to collect data. Systematic verbal and behavioral communications between the subject and investigator and between the subject, investigator and others were noted in detail on a Process Recording Worksheet after each interview was completed. The investigator found that the interviews increased in length with each additional contact made; therefore many of the later interviews were tape recorded and transcribed in place of recalling the encounter in field notes.

TABLE I: DESCRIPTIVE INFORMATION OF THE SUBJECTS WITH NONRESECTABLE LUNG CANCER

Subject	Sex	Age	Date of Initial Interview	Date Diagnosed	Date of Death
Carl*	M	80	6.8.74	6.17.74	7.4.74
Elmer	M	77	7.23.74	7.19.74	12.1.74
Walter	M	62	7.10.74	7.2.74	11.12.74
Joe	M	61	7.15.74	7.16.74	8.22.74
Fred	M	59	7.9.74	4.17.74	8.15.74
Herbert	M	56	8.9.74	8.16.74	9.18.74
Doris	F	37	8.27.74	6.28.74	11.13.74
Rebecca	F	26	7.9.74	6.17.74	8.25.74

*Names have been changed to maintain anonymity

The investigator was aware from her professional experience as a nurse that the medical regimen used in the treatment and control of the patients' disease and its effectiveness influenced the subjects' perceptions and understanding of their illness; therefore the subjects' medical records during hospitalizations and clinic visits were reviewed in order to establish a framework from which the subjects perceived their illness. In addition, the review of records helped to substantiate and clarify the subjects' perception of their illness. Consent was obtained from the subjects in order for them to participate in the study and to review their medical records.

Data Analysis:

Even though there has been interest in the dying process of humans by several investigators[15] over the past several years, much of the research has dealt with the person dying and not the relational aspect of the person dying within a family context.[16] Therefore, the data obtained by participant observations was synthesized by the case study method in order "to obtain the widest variety of information about each case and to obtain the kind of depth information which cannot usually be obtained about large numbers of respondents because of the difficulty and time involved in obtaining such data."[17]

In order to present each case study in a consistent and systematic manner, the investigator and another person experienced in recognizing behavior changes independently coded the data on the worksheet. The coders examined the field notes for behaviors and verbal statements that demonstrated communication patterns and changes between the subjects and others. These behaviors and verbalized thoughts were interpreted not only as unique characteristics of the subjects, but also as a relational unit of exchange

and/or feeling between the individuals involved. A comparative analysis between subjects for differences and similarities was done.

Findings:

There were ninety-one semi-structured interviews completed over an eight month period from June, 1974 through January, 1975. (See Table II for the number of interviews with each subject.) One of the outcomes of this present study was to determine to what extent the health care professionals, the individual's family, and the subject with cancer act as if the subject's cancer is controllable. For purposes of this paper, health care professionals refer to the physicians directly responsible for the subject's medical care. None of the subjects identified their physicians as one of the five most important people to them; therefore the physicians were not interviewed. Much of the data about the physician's behavior was obtained from the subjects' ability to recall what they were told. Baseline data of the medical regimen was obtained by reviewing the clinical progress notes of each subject's medical record. This review allowed the investigator to identify what the physicians had recorded they had told the subjects and, in addition, it helped to substantiate the subjects' perceptions of their ilness.

Examination of the eight subjects revealed that they were all married, midwestern Caucasians. Their ages ranged from twenty-six years to eighty. All six males had children, but neither of the females did. The two women were the youngest of the subjects.

Certain trends appear in the collected data. All were told immediately that they had cancer, but the degree of uncertainity associated with their prognosis was obscured and unpronounced. One group of subjects, Carl, Elmer, Walter, and Doris not only knew their diagnosis but they knew they were going to die soon.

TABLE II: INTERVIEW RECORD

Subject	Interview Setting				Number of Interviews			
	Hospital	Clinic	Home/ Other	Telephone	Subject	Subject with Other	Others Alone**	Total
Carl*	3	0	1	0	1	2	1	4
Elmer	10	0	1	1	10	1	1	12
Walter	15	1	1	2	12	4	3	19
Joe	12	0	1	1	5	6	3	14
Fred	9	0	1	1	2	6	3	11
Herbert	10	1	1	0	7	2	3	12
Doris	2	2	4	1	3	1	5	9
Rebecca	5	3	2	0	4	3	3	10
Totals	66	7	12	6	44	25	22	91

*Names have been changed to maintain anonymity.
** "Others alone" refers primarily to the persons that the subjects identified as important, but in the cases of Walter, Joe, Doris, and Rebecca a hospital employee was interviewed.

(See Table III for a summary of the behavior of the physicians and subjects during illness.) Carl was told immediately that treatment would not help him because of his age, and yet he was given a one month return appointment. He died two weeks later. Similarly Elmer was the same age as Carl, but the physicians treated him with radiation therapy to stop the bleeding from his lungs. Walter was eighteen years younger than Carl and Elmer, but he had been forced to retire early because of his chronic lung disease. He had come to rely on the doctors at Veteran's and his encouragement of their abilities secured him treatment. Doris' marriage had been a mistake but one that she had learned to endure. Her life was centered around her work as a nurse's aide and as soon as her doctor told her she had cancer she knew death was not far off.

In contrast, the other group of Joe, Fred, Herbert, and Rebecca struggled continually with their deterioration and dying. Cancer was unexpected and certainly they viewed their death as premature. They had no experience with illness and had come to believe that in this day and age of modern medicine something could be done.

Carl was the only subject told by the physicians that his cancer would end his life soon; the remaining seven subjects were told that they would be treated for their cancer. According to the subjects' spouses, none of the seven were informed by the University physicians that they were dying. And yet, all of the spouses had been informed by one or more physicians that the treatment had not been as effective as they had hoped. None of the subjects with their spouses were seen by the same resident physicians when they returned. (See Table IV for a summary of the pattern of subject contact with health care professionals.) Walter was the only subject who died on the same unit where he was diagnosed. This inadvertently occurred before his transfer to a nursing home was completed.

TABLE III: BEHAVIOR OF PHYSICIANS AND SUBJECTS DURING ILLNESS

Subject	Behavior of Health Care Professionals	Subject's Behavior
GROUP I:		
Carl	Told he had cancer immediately; not treated. Given return clinic appointment.	Expected to die because of age; news of cancer was confirmation of suspicions; brought closure to life in a way that was satisfying to him and family.
Elmer	Told immediately, but treated with radiation to control bleeding. Given return clinic appointment.	Bleeding alerted subject; knew something serious was wrong; expected to die; brought closure to life in a way that was satisfying to him and family.
Walter	Told immediately, but treated with radiation to control his seizures. Given return clinic appointment.	Had not been well for years, knew he would eventually die; brought closure to life in a way that was satisfying to him and family.
Doris	Told immediately, treated with chemo-therapy. Given return clinic appointment.	Had previous occupational experience; realized she would soon die. Had little to look forward to except work; worked as long as possible. Her co-workers and siblings helped to bring closure to life in a way that was satisfying to her and them.

Table III-Continued

Subject	Behavior of Health Care Professionals	Subject's Behavior
GROUP II:		
Joe	Told him cancer could be controlled by radiation; was not told cancer spread to liver. Given return clinic appointment.	Cancer came as a shock because it was unexpected; no previous experience with illness; withdrew from his attachments; became nonverbal and immobile; died quickly as if to relieve his misery.
Fred	Told him cancer could be controlled by radiation; only subject to receive two series of radiation treatments. After second series, not given return appointment.	Cancer came as a shock because it was unexpected; no previous experience with serious illness. Withdrew from all his previous attachments except his wife. Their conversation was limited to the identification of comfort measures for him. As his death was imminent his wife let go and became detached. Fred died slowly, not wanting to go.
Herbert	Told him they would try to help with chemotherapy. After first clinic visit, wife told not to return.	Cancer came as shock because it was unexpected. No previous experience with illness. Withdrew from his attachments. Became incoherent and immobile. Wife let go; became detached and died alone.
Rebecca	Told immediately; but told that cancer could be controlled by chemotherapy. Given return appointments weekly.	Cancer came as shock because it was unexpected. No previous personal experience with illness. Had no understanding of what was happening. Attachments deteriorated. Died quickly, realizing that she had not brought closure to her life in a satisfying way.

TABLE IV: PATTERN OF SUBJECT CONTACT WITH PHYSICIANS

Subject	Date First Seen*	Initially Seen By*	Initial Hospitalization*
GROUP I:			
Carl	5.31.74	Pulmonary Clinic Veterans	6.3.74 Veterans
Elmer	7.5.74	Local M.D.	7.74 Local Hospital
Walter	6.26.74	Local M.D.	6.26.74 (6 days) Local Hospital
Doris	5.74	Local M.D. Biopsy 6.28.74 as out-patient	Treated by local M.D. with chemotherapy (5 weeks) Admitted 8.21.74
GROUP II:			
Fred	4.8.74	Local M.D.	4.15.74 University
Joe	5.1.74	Local M.D.	5.28.74 Veterans
Herbert	7.24.74	Local M.D.	Local hospital (1 week)
Rebecca	5.29.74	Student health	6.6.74 University Diagnosed by biopsy as outpatient

*For illness related to cancer diagnosis only

Table IV --Continued

Subject	Admission to University Complex	Length of Hospitalization at University	Patient Areas and Medical Service
GROUP I:			
Carl	Initial admission 6.3.74	17 days	Seventh Pulmonary
Elmer	Transferred to VA 7.15.74	30 days	Seventh Pulmonary Radiation
Walter	Transferred to VA 7.1.74 2nd ad. 10.18.74	1. 33 days 2. 24 days	Seventh Pulmonary Radiation
Doris	Referred to Univ. 8.21.74 - Initial admission 2nd ad.10.24.74	1. 8 days 2. 5 days	1.Fifth Surgery 2.Third Oncology
GROUP II:			
Fred	Referred 4.17.74 2nd ad. 6.18.74	1. 32 days 2. 31 days	1.Second- Surgery 2.Fifth Radiation
Joe	Initial ad. V.A. 5.28.74 Transf. to Univ. 7.10.74 for OR Returned to V.A. 7.17.74	74 days	Seventh Pulmonary Six-Un.Hosp Surgery Seventh Radiation
Herbert	Transf. to Univ. 8.1.74	27 days	Third Surgery Oncology
Rebecca	Initial ad. 6.17.74 2nd ad. 7.13.74 3rd ad. 7.23.74 4th ad. 8.22.74	1. 10 days 2. 3 days 3. 2 days 4. 3 days	1.Third Medicine Second Surgery 2.Fifth Oncology 3.Fifth Oncology 4.Third West

Table IV --Continued

Subject	Scheduled Return Clinic Visits	Last Clinic Visit Scheduled	Date and Place of Death	Length of Final Hospitalization
GROUP I:				
Carl	-	8.8.74	7.7.74 Home	-
Elmer	10.4.74	12.13.74	12.1.74 Local Hospital	5 days
Walter	9.6.74	Return in 3 mo.	11.12.74 V.A.	24 days
Doris	9.6.74 9.20.74 9.27.74 10.2.74 10.18.74	11.15.74	11.13.74 Local Hospital	4 days
GROUP II:				
Fred	6.18.74	None scheduled	8.15.74 Local Hospital	6 days
Joe	-	9.10.74	8.22.74 Home	-
Herbert	9.6.74	None	9.18.74 Local Hospital	2 days
Rebecca	6.29.74 7.10.74 8.2.74 8.9.74 8.16.74	8.23.74	8.25.74 University	3 days

All eight were given an initial return appointment after their diagnosis and first hospitalization. Six had return appointments scheduled after they had died. However, two subjects, Fred and Herbert, had become so physically incapacitated the physicians told their wives that if they needed medical assistance for their husbands to contact their local physicians. Neither subject was told why it was not necessary to return.

Discussion

The patient-physician communications reported in this paper have been presented in oversimplified statements which are in reality extremely complex. Of necessity, a good many clarifying and explanatory details have not been included. What follows is a limited discussion of the findings related to communicating with patients and their families.

Cancer by its very nature is unpredictable. The prognosis is more difficult to ascertain than the diagnosis and the outcomes of some cancers are more easy to predict than others. In comparison with other cancers, relatively few patients with lung cancer will survive after symptoms. Clearly, physicians cannot be absolutely certain of the prognosis; mainly because they are unclear what course the disease may take in one patient verus another. Because of this uncertainity, what can the patient and his family be helped to understand? One of the major indications of this study is the coming to terms with cancer takes time. A single encounter with a patient to tell him that he has cancer and that little can be done medically most likely will not be heard and/or understood by the patient.

The findings of this study suggest that the physicians are more likely to tell an old man rather than a young one that he is going to die soon. Intuitively, physicians tell the aged because they feel the elderly man can handle it and that they may expect it. In addition, the data suggest that physicians may be

able to tell a person that his future is limited if he has been chronically ill over a period of time or if he views his life as unfulfilling or of little value. For the two elderly men, they found it unnecessary to talk openly about their dying. For Walter and Doris, they talked openly about dying and they were actively involved in planning their remaining days. The openness associated with Doris' dying was initiated and maintained by her own knowledge and efforts. She knew that her future was limited because she had cared for patients with similar diagnoses. She knew what to expect and she knew she had to bring closure to her family members soon if she wanted to have that opportunity. If she had not known that a diagnosis of lung cancer meant a shortened life for her, she might have struggled with death similarly as the other four subjects did.

None of the subjects had a clear understanding of the purpose of their continued medical treatment. Rubin states that in the advancing period of cancer "the suppression of the disease activity and long remissions are the aims of therapy."[18] It was clear that these subjects were not told the extent of their disease process. At the time of their return visits, the subjects had to wait several hours to be seen for fifteen minutes by a physician they had never seen before. Each subject was asked about his symptoms but none was asked directly how he and his family were managing. Once the subjects were in the presence of the physician, they described the experience as becoming paralyzed by what they would hear next. They shared they could not muster up enough courage to formulate their concerns into questions to a person they did not know.

All subjects were given a return appointment, eventhough only one subject lived in the vicinity of the medical center; the others lived over sixty miles away. The purpose of the continued appointments was not clear to the investigator and several subjects asked why it was necessary. One intent of a scheduled future-oriented return appointment might be to convey to the patient a sense of

hope that he has a future. A question yet to be answered is how frequently patients should be seen, by whom, and where if their prognosis is uncertain. The energies needed by the patients to maintain their contact with the medical center may not justify the gains the patients receive. For these eight subjects, once their disease became irreversible, they were no longer given an opportunity to have a choice to continue treatment or to terminate their visits. The choice was made for them. At times it was clear that the physicians continued to behave as if the subjects had an unlimited future.

The results of these data suggest that different communication strategies are needed to help the individual and his family cope with what is happening to them. The approach for the elderly is different from that for the young. Not only is the openness about the patient's cancer diagnosis crucial, but also the extent of the patient's cancer and his prognosis must be considered. Certain patient situations are more vulnerable to difficulties in coping with cancer than others. The young twenty-six year old woman was especially vulnerable to problems in adjusting to her limited future and bringing closure to her life. All three men in their fifties and early sixties had difficulty accepting their limited future because cancer was unexpected. In addition, if the patient or his family have had a previous experience with cancer, their knowledge of the disease and its consequences should be used to enhance, rather than interfere with, the quality of their remaining days together.

One alternative to our present system of communicating with patients would be to study whether a consistent health care professional providing opportunities for the patients and their families to discuss their concerns as they occur or before they occur makes a difference. If patients with advanced cancer are to be seen at medical centers, it would seem that the return appointments may be an appropriate time to help them deal with what is happening to them. In addition, the resident physician rotating through a medical serivce may not be the most

benefical person to support the patient and family. The waiting time in the clinics would be an ideal time to see patients in a consistent fashion to help them redefine their hopes over time.

Footnotes

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8. _____, "Psychological Considerations in the Care of Patients with Cancer," Annals New York Academy of Science, Volume 25 (1966),p. 1026.

9. For a description of basic data about cancer, see '76 Cancer Facts and Figures (New York: American Cancer Society, Inc, 1975), pp. 3-4.

10. B. Cobb, "Emotional Problems of Adult Cancer Patients," Journal American Geriatric Society, Volume 7 (1954), pp. 920-926.

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Distress of the Dying," Quarterly Journal of Medicine, Volume 32 (January, 1963), pp. 1-21.

14. Marion Pearsall, "Participant Observation as Role and Method in Behavioral Research," Nursing Research, Volume 14 (Winter, 1965), pp. 37-42.

15. See as examples: Elisabeth Kubler-Ross, On Death and Dying (New York: The Macmillan Company, 1969) and Barney G. Glaser and Anselm L. Strauss, Awareness of Dying (Chicago: Aldine Publishing Company, 1965).

16. In order for a relationship to develop, one of the individuals involved must have a conceptual model, either consciously or unconsciously, that the assumed relationship exists. Relationships begin and develop by intercommunication. A relationship is established when the context in which the phenomenon occurs is taken into account with the phenomenon; the individuals intercommunicating are taking into account the manifestations of the relationship by the process of communication.

17. David J. Fox, Fundamentals of Research in Nursing, 2nd edition (New York: Appleton, Century, Crofts, 1970), p. 189.

18. P. Rubin, "Advanced Hodgkin's Disease: Chemotherapy, Radiotherapy and Special Considerations in Pregnancy and Childhood," Journal American Medical Association, Volume 191 (1965), p. 318.